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Health-related quality of life and health care utilisation among older long-term cancer survivors: A population-based study

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ABSTRACT

Background: The consequences of cancer and its treatment on health-related quality of life (HRQL) and health care utilisation among *elderly* long-term cancer survivors have rarely been studied. However, the impact can be different for older compared to younger patients due to the higher prevalence of comorbid diseases, a higher risk of treatment-related complications and because they often receive different therapies compared to younger patients. Therefore, this study addressed the following questions; do HRQL and health care utilisation differ between younger and elderly cancer survivors, and are those differences age or disease related.

Methods: A population-based, cross-sectional survey among 1893 long-term survivors of endometrial cancer, prostate cancer and non-Hodgkin's lymphoma was conducted using a cancer registry. HRQL was measured by the SF-36 and health care utilisation was measured with a self-reported questionnaire. Results were compared to a normative population. Patients with disease progression were excluded resulting in a total number of 1112 patients to be analysed.

Results: Young non-Hodgkin lymphoma survivors (<70 years) reported lower vitality, bodily pain and general health compared to the normative population while older (⩾70 years) survivors did not differ from the norm. Young lymphoma survivors experienced better physical functioning compared to older survivors. Young endometrial cancer survivors experienced less bodily pain compared to the normative population while older survivors did not differ from the norm. Young endometrial cancer survivors experienced better physical and role functioning compared to older survivors. Young prostate cancer survivors reported less bodily pain compared to the norm while older survivors did not. Young prostate cancer survivors reported higher scores on physical functioning compared to older survivors. Age, comorbid diseases, educational level and current occupation influenced HRQL significantly. Both younger and older cancer survivors visited their medical specialist, but not their GP, significantly more often compared to the age-matched general Dutch population. Both younger and older cancer survivors only sporadically used additional care services after cancer treatment.

Discussion: HRQL of older and younger survivors is comparable, with the exception of physical functioning which is lower in older survivors. This difference in physical functioning was probably not caused by cancer because physical functioning among cancer survivors did not differ much compared to an age-matched normative population. Both younger

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and older long-term cancer survivors visited their medical specialist often but only sporadically used additional care services after cancer treatment.

1. Introduction

Due to the increasing incidence of cancer in general, the ageing of the population and more effective cancer treatments the prevalence of cancer is rising.[1] Cancer is changing from a life-threatening disease into a chronic condition.[2] A large number of cancer patients will therefore become long-term survivors: i.e. those alive 5 years after initial diagnosis.[3] Because the incidence of most types of cancer is age-dependent and the risk of developing a tumour is progressively higher with increasing age, the mean age of cancer survivors is increasing. Based on data from the Netherlands Cancer Registry, the Dutch Cancer Society estimated that in the year 2000, the prevalence of cancer among patients older than 64 was about 215,000. This prevalence is expected to double to 430,000 in the year 2015.[1] In younger cancer patients (15–64 year) these numbers are 149,000 and 273,000, respectively. This illustrates the rapid increase in the numbers of *elderly* patients who are either cured of their cancer or living with it as a chronic disease.

Cancer and its treatment can have a significant effect on a patient's life during diagnosis and treatment but also years after the treatment has been completed. For example, prostate cancer patients had comparable health-related quality of life (HRQL) scores but worse general health perceptions and better mental health than an age-matched normative population.[4] In addition, long-term non-Hodgkin lymphoma survivors experienced lower general health and felt less vital compared to an age-matched normative sample.[5] Finally, endometrial cancer survivors treated with surgery and adjuvant radiotherapy felt less vital compared to patients treated with surgery alone.[6]

The consequences of these effects on HRQL and health care utilisation among *elderly* long-term cancer survivors have rarely been studied separately from results of younger cancer survivors and additionally, elderly patients are often excluded from clinical trials. However, the impact of cancer and its treatment can be different for older compared to younger patients due to a number of reasons including the higher prevalence of comorbid diseases,[7] a higher risk of treatment-related complications[8] and the fact that older patients often receive different therapies[7,9,10] compared to younger patients.

The aim of the present population-based study was to obtain insight into the HRQL and health care utilisation of elderly long-term cancer survivors by comparing our data of patients under the age of 70 with results of those aged 70 and older. Furthermore, we compare the HRQL and health care utilisation of these younger and older survivors with that of an age- and gender-matched normative population. Because our previous articles on long-term prostate cancer, endometrial cancer and non-Hodgkin's lymphoma survivors did not focus especially on the *elderly*, we combined the data of these studies in this study.[4–6]

2. Patients and methods

2.1. Setting and participants

A population-based, cross-sectional survey was conducted at the Eindhoven Cancer Registry (ECR). The ECR records data on all patients newly diagnosed with cancer in the southern part of the Netherlands, an area with 2.3 million inhabitants, 10 hospitals, with 18 hospital locations and two radiotherapy institutes.[11] The ECR was used to select all patients diagnosed with prostate cancer or endometrial cancer between 1994 and 1998 and all patients diagnosed with non-Hodgkin's lymphoma between 1989 and 1998. Data on NHL were collected over a longer period of time because negative side-effects of NHL often occur at a later stage.

Participants older than 75 years *at diagnosis* were excluded as it was expected that they would have difficulty in completing a self-report questionnaire without assistance. However, as the questionnaire was distributed 5–15 years after diagnosis we were still able to include large numbers of elderly. To exclude all persons who had died before November 1st, 2004, our database was linked to the database of the Central Bureau for Genealogy, which collects data on all deceased Dutch citizens via the civil municipal registries. After having excluded all persons who had died, data collection was started in November 2004. Approval for this study was obtained from a local certified Medical Ethics Committee.

2.2. Data collection

Medical specialists sent their (former) patients a letter to inform them about the study, together with the questionnaire. The letter explained that, by returning the completed questionnaire, the patient agreed to participate and consented to linkage of the questionnaire data with their disease history as registered in the ECR. Patients were reassured that non-participation would not have any consequences for their follow-up care or treatment. If the questionnaire was not returned within two months, a reminder-letter with an additional copy of the questionnaire was sent.

2.3. Measures

The ECR routinely collects data on tumour characteristics, including date of diagnosis, grade, clinical stage,[12] treatment and patient background characteristics like date of birth. The questionnaire also included questions on sociodemographic data, including marital status, current occupation, educational level as well as disease progression and current comorbidity.

The Dutch version of the SF-36 questionnaire was used to assess HRQL.[13] It incorporates two composite scales – the Physical Component Scale (PCS) and the Mental Component

Scale (MCS)[14] – derived from eight domains: physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), general health perceptions (GH), vitality (VT), social functioning (SF), role limitations due to emotional problems (RE) and general mental health (MH).[15] The internal consistency reliability estimates of all scales were above the criteria recommended for group comparisons (Cronbach's $\alpha = 0.70$). According to standard scoring procedures, all scales were linearly converted to a 0–100 scale, with higher scores indicating better functioning.

The SF-36 has been shown to be a valid measure of HRQL in a population more than the age of 70 years.[16] Furthermore, the SF-36 is able to discriminate between patients who had a diagnosed malignancy and patients who did not have a known cancer diagnosis.[17] We used Norman's 'rule of thumb' that the threshold of discrimination for changes in HRQL for a chronic disease appears to be approximately half a SD.[18]

The SF-36 scores of the patient sample were compared with those of an age-matched normative sample. This age-matched sample was drawn from a nationwide sample of Dutch adults ($n = 1742$) in which questionnaires were mailed to a sample of households drawn at random from the national telephone registry.[15] The SF-36 was mailed to 2800 households. Non-respondents were sent reminder letters after 2 months and 3 months following the initial mailing. In total, 1771 questionnaires were returned, representing a 63% response rate.

This study was done in the Netherlands, a country in which every person has equal access to care. After treatment, patients go to their specialist for control visits for a number of years and this varies by site. Endometrial cancer survivors are followed up until 5 years after diagnosis. Prostate cancer patients are followed up until 10 years after diagnosis. Patients with non-Hodgkin's lymphoma are in follow-up for at least 5 years. However, it is well accepted to keep them under specialist surveillance for a longer period of time (Dutch guidelines; http://www.oncoline.nl).

The items concerning health care utilisation included questions on the number of visits to a general practitioner (e.g. primary care physicians) and medical specialist (including those specialists involved in cancer care) in the past 12 months. These questions were asked in a similar way as is done via the annual monitoring of the health care situation of a random sample ($N = \pm 10{,}000$) of the Dutch population by Statistics Netherlands (http://statline.cbs.nl). Furthermore, patients were asked the following question; '*After cancer treatment*, did you receive any additional care for cancer-related problems? If yes, please indicate the kind of additional care from the list below'. The list included a dietician, psychologist, sexologist, pastoral care, creative therapy, recovery programme, oncology nurse, physiotherapist and contact with other cancer survivors.

2.4. Statistical analyses

All statistical analyses were performed using SAS (version 9.1 for Windows, SAS institute Inc., Cary NC). Routinely collected data from the ECR on patient and tumour characteristics enabled us to compare the group of respondents, non-respondents and patients with unverifiable addresses, using the χ^2-test for categorical variables. Sociodemographic and clinical characteristics of patients with different types of cancer are given in percentages.

Linear regression analyses were carried out in order to investigate the association between patient characteristics (age, comorbidity) and tumour characteristics (stage, treatment, time since diagnosis) with the composite and subscale scores of the SF-36. On the basis of the univariate results, multivariate models were constructed to determine which of the patient and tumour characteristics were associated independently with HRQL outcomes. We controlled for these variables in the analysis of covariance (ANCOVA), which was used to compare means of SF-36 scores between different age groups.

Multivariate linear regression analyses were carried out to investigate the independent association between sociodemographic (age, comorbidity, marital status, education and occupation) and clinical variables (time since diagnosis, stage, grade, treatment) and the SF-36 scale scores, using a p-value of <0.01 as statistically significant. We applied multivariate regression analyses in both age groups separately as we were interested to see if different factors would be associated with HRQL in older and younger survivors. Because the choice of treatment is associated strongly with age, we hypothesised that treatment would have a different association with HRQL in younger than in older survivors. The independent variables were categorised as follows. Age and time since diagnosis were entered as continuous variables. Tumour stage was entered as stages I (reference category), II, III, IV, unknown. Therapies were entered as therapies (reference category) versus no therapies, for example radiotherapy versus no radiotherapy. Comorbidity was entered as comorbidity (reference category) versus no comorbidity. Marital status was entered as married (reference category), not married, divorced. Education was entered as high (reference category) versus low. Occupation was entered as work (reference), no work, retired.

The percentages of patients visiting a general practitioner or medical specialist in the past 12 months were compared to the percentage of people from the general population visiting these health care professionals. This comparison was made according to the type of tumour and according to the age at the time of answering the questionnaire; for both survivors younger than 70 and those older than 70 years of age an age- and gender-matched reference group from the general population was formed. Percentages were compared using binomial distributions.

3. Results

3.1. Sociodemographic and medical characteristics

One thousand three hundred and seventy nine (80%) of 1729 patients returned a completed questionnaire (Fig. 1). A comparison of respondents, non-respondents and patients with unverifiable addresses indicated that the non-respondents were significantly older, more often diagnosed with stage I disease and less often treated with chemotherapy than respondents (Table 1). A number of these respondents were excluded from the primary analyses because they exhibited disease progression (90 new primary tumour, 110 metastasis

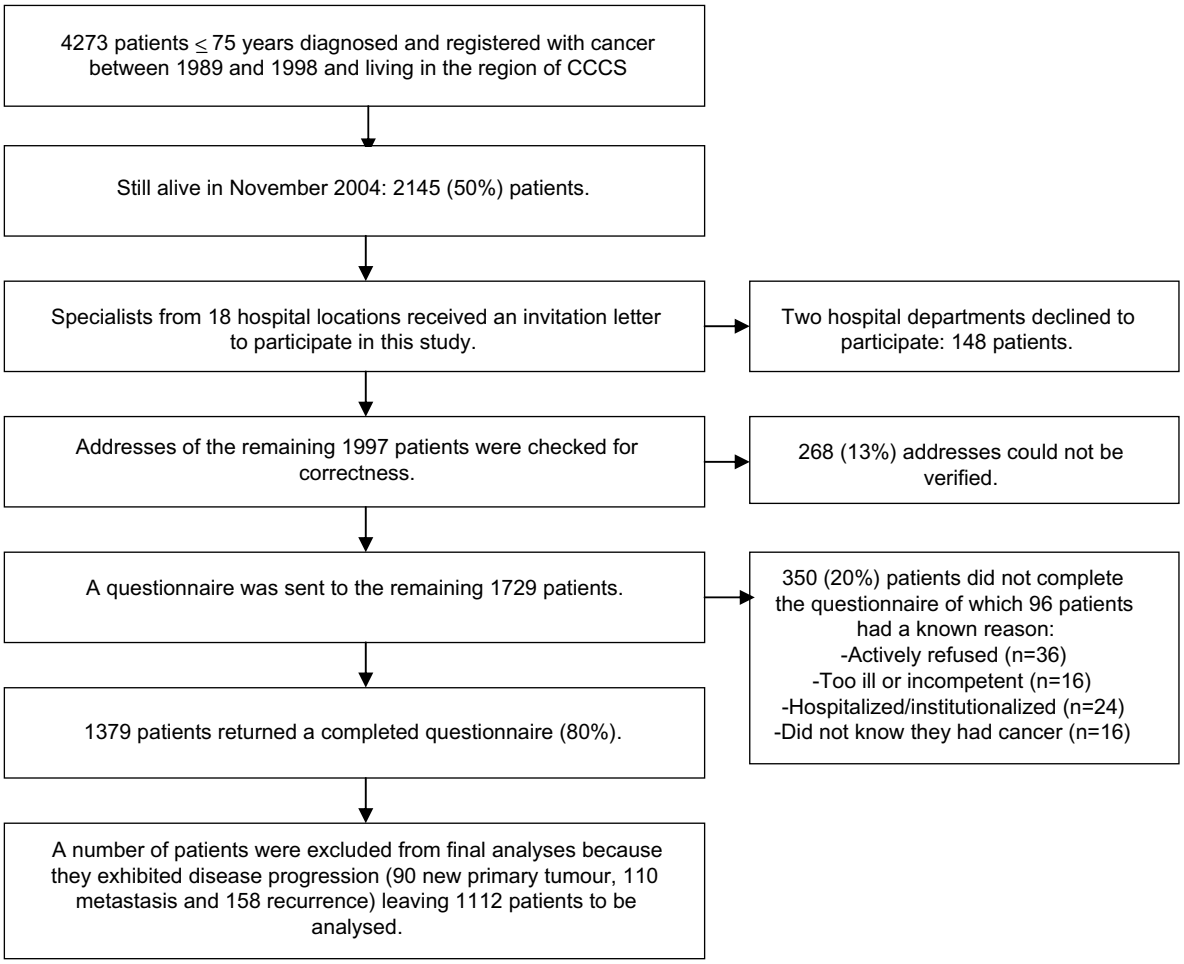

Fig. 1 – Flow-chart of the data collection process.

and 158 recurrence), resulting in 1112 patients to be analysed. Sociodemographic and clinical characteristics of cancer survivors, according to age group and type of tumour, are presented in Table 2. In patients with indolent lymphoma, the disease will be recurrent or progressive, dependent on the grade of remission induced by treatment (complete or partial remission). This is different from aggressive lymphoma, where cure is the aim and a possible treatment result. In this study, 4 patients (2%) were diagnosed with uncommon non-Hodgkin lymphoma, 58 patients (26%) were diagnosed with indolent lymphoma, 137 patients (61%) with aggressive lymphoma and 26 patients (12%) were diagnosed with another or unknown grade.

3.2. *Young versus old cancer survivors*

Young non-Hodgkin lymphoma survivors reported higher scores on the subscales physical functioning (77.4 versus 60.5; $p < 0.01$) compared to older lymphoma survivors (Table 3) and this difference was clinically meaningful. Differences were also found for mental health, role-physical functioning and the physical and mental component scales but although they were statistically significant, they were not clinically meaningful.

Young endometrial cancer survivors experienced higher scores on the subscales physical functioning (77.2 versus 51.2; $p < 0.001$), role-physical functioning (71.5 versus 51.1; $p < 0.05$), and on the physical component scale (47.6 versus 39.7; $p < 0.001$) compared to older endometrial cancer survivors and these differences were also clinically meaningful.

Young prostate cancer survivors reported higher scores on the subscale physical functioning (77.7 versus 65.1; $p < 0.001$) compared to older prostate cancer survivors and this effect was clinically meaningful (Table 3). Furthermore, young prostate cancer survivors reported higher scores on mental health, role-physical functioning, and the physical and mental component scales compared to older survivors but these effects were only statistically significant and not clinically meaningful.

3.3. *Cancer survivors versus a normative population*

Non-Hodgkin lymphoma survivors under the age of 70 were less vital (61.4 versus 68.8; $p < 0.01$), experienced less bodily pain (81.6 versus 72.4; $p < 0.01$) and a lower general health perception (57.6 versus 68.6; $p < 0.001$) compared to an age- and gender-matched normative population and these differences were clinically meaningful (Fig. 2). Lymphoma survivors aged

Table 1 – Sociodemographic and medical characteristics of questionnaire respondents, non-respondents and patients with unverifiable addresses

	N (%)			p-Value
	Respondents, N = 1379	Non-Respondents, N = 350	Patients with unverifiable addresses, N = 268	
Mean age at time of survey	70 years	71 years	67 years	
Age at time of survey				
<65 years	347 (25)	69 (20)	82 (31)	0.0029
65–75 years	534 (39)	123 (35)	98 (37)	
75+ years	498 (36)	158 (45)	88 (33)	
Years since diagnosis				
5–9 years	1241 (90)	310 (89)	230 (86)	0.1216
10–15 years	138 (10)	40 (11)	38 (14)	
Stage at diagnosis				
I	594 (43)	189 (54)	114 (43)	0.0002
II	528 (38)	97 (28)	88 (33)	
III	61 (4)	20 (6)	18 (7)	
IV	127 (8)	20 (6)	25 (9)	
Unknown	69 (5)	24 (7)	23 (9)	
Treatment				
Surgery	718 (52)	199 (57)	129 (48)	0.0906
Radiotherapy	552 (40)	127 (36)	96 (36)	0.2453
Hormonal therapy	211 (15)	51 (15)	30 (11)	0.2195
Chemotherapy	212 (15)	37 (11)	47 (18)	0.0317
Wait and see	84 (6)	24 (7)	24 (9)	0.2205

70 and older did not differ significantly from the normative population.

Endometrial cancer survivors under the age of 70 experienced less bodily pain compared to the age- and gender-matched normative population (76.8 versus 68.0; $p < 0.001$) and this effect was clinically meaningful. Furthermore, they reported higher scores on physical functioning and the physical component scale but these effects were only statistically significant and not clinically meaningful. Endometrial cancer survivors aged 70 and older did not differ significantly from the normative population.

Prostate cancer survivors under the age of 70 were compared with an age- and gender-matched normative population and they reported less bodily pain (82.7 versus 72.5; $p < 0.001$), which was clinically meaningful. Furthermore, survivors aged 70 and older reported lower scores on general health perception and reported less bodily pain but these effects were only statistically significant and not clinically meaningful.

3.4. *Multivariate linear regression analyses*

The results of the multivariate linear regression analyses, with the SF-36 scales as outcome variables, are reported as beta coefficients for patients <70 and ⩾70 years. In cancer survivors younger than 70, comorbidity was negatively associated with the majority of the SF-36 subscales (Table 4). Furthermore, education was positively associated with physical functioning and occupation was positively associated with role-physical functioning, role-emotional functioning and general health perception. In older cancer survivors, age was negatively associated with physical functioning, role-physical functioning, social functioning, role-emotional functioning and the physical component scale. Comorbidity was negatively associated with all SF-36 subscales. And finally, occupation was positively associated with general health, vitality and the physical component scale.

3.5. *Health care utilisation*

The percentage of people having contact with a general practitioner and a medical specialist in the past 12 months was compared between young (<70) and old (⩾70) cancer survivors (non-Hodgkin lymphoma, endometrial cancer and prostate cancer) with an age- and gender-matched normative population (Table 5). The percentage of cancer survivors who visited their general practitioner was comparable to that of the general age-matched normative population for both younger and older survivors. However, the percentage of survivors who visited their medical specialist was significantly higher compared to the age- and gender-matched sample from the normative population and this holds for both the younger and older age groups. Cancer survivors only sporadically (0–4%) used the following additional care services after cancer treatment: dietician, psychologist, sexologist, social worker, pastor, creative therapy, recovery programme, oncology nurse, physiotherapist and contact with other cancer survivors (data not shown). There were no differences in use of additional care services between younger and older cancer survivors.

4. Discussion

The aim of the present study was to describe the HRQL and health care utilisation among long-term cancer survivors

Table 2 – Sociodemographic and medical characteristics of long-term cancer survivors without recurrent disease or new primary malignancies

	Non-Hodgkin's lymphoma		N (%) Endometrial cancer		Prostate Cancer	
	<70 years, N = 155	⩾70 years, N = 70	<70 years, N = 177	⩾70 years, N = 106	<70 years, N = 135	⩾70 years, N = 469
Mean age	53	76	63	76	66	77
Gender						
Male	83 (54)	33 (47)	0 (0)	0 (0)	135 (100)	469 (100)
Female	72 (46)	37 (53)	177 (100)	106 (100)	0 (0)	0 (0)
Stage at diagnosis						
I	56 (36)	35 (50)	157 (89)	92 (87)	42 (31)	130 (28)
II	34 (22)	15 (21)	9 (5)	13 (12)	79 (59)	276 (59)
III	16 (10)	3 (4)	6 (3)	1 (1)	5 (4)	13 (3)
IV	41 (26)	11 (16)	1 (1)	0 (0)	5 (4)	20 (4)
Unknown	8 (5)	6 (9)	4 (2)	0 (0)	4 (3)	30 (6)
Primary treatment[a]						
Surgery	22 (12)	6 (14)	221 (99)	59 (98)	188 (64)*	108 (35)
Radiotherapy	85 (46)	17 (40)	68 (30)	23 (38)	113 (39)*	163 (52)
Hormonal therapy	0 (0)	0 (0)	1 (1)	0 (0)	20 (15)*	133 (28)
Chemotherapy	115 (74)	45 (64)	4 (2)	0 (0)	0 (0)	0 (0)
Wait and see	12 (8)	4 (6)	0 (0)	0 (0)	5 (4)	33 (7)
Comorbidity	*				*	
None	92 (50)	11 (26)	62 (28)	16 (27)	120 (41)	103 (33)
1 or more	91 (50)	31 (74)	161 (72)	44 (73)	173 (59)	208 (67)
Most frequent comorbid conditions						
1. Hypertension	22 (14)*	22 (31)	56 (32)*	48 (45)	36 (27)	138 (29)
2. Arthrosis	25 (16)*	23 (33)	65 (37)	42 (40)	28 (21)	107 (23)
3. Asthma	12 (8)	9 (13)	21 (12)	11 (10)	13 (10)	71 (15)
Marital status	*		*		*	
Married	112 (75)	39 (60)	128 (74)	46 (46)	110 (85)	352 (79)
Not married/divorced	30 (20)	9 (14)	20 (12)	7 (7)	12 (9)	24 (5)
Widowed	7 (5)	17 (26)	24 (14)	46 (46)	7 (5)	72 (16)
Educational level	*		*		*	
Primary school	56 (38)	38 (59)	90 (52)	72 (74)	44 (34)	216 (49)
Secondary school	49 (33)	18 (28)	62 (36)	18 (19)	45 (35)	145 (33)
College/university	42 (29)	8 (13)	21 (12)	7 (7)	41 (32)	82 (19)
Occupation	*		*			
Employed	67 (45)	0 (0)	30 (17)	3 (3)	20 (16)	6 (1)
Unemployed	47 (32)	12 (18)	86 (50)	50 (51)	10 (8)	6 (1)
Retired	34 (23)	53 (82)	57 (33)	45 (46)	99 (77)	418 (94)

The reported characteristics all refer to the time of survey unless stated otherwise.
a Patients can be treated with a combination of treatments, therefore, the percentages do not add up to one hundred.
* $p < 0.05$ difference between those <70 years of age and those 70 years and older.

aged 70 and older and to compare it to those younger than 70 years of age and to an age-matched normative population. HRQL of older and younger survivors is comparable, with the exceptions of physical functioning which is lower in older survivors. This difference in physical functioning was probably age-related and not caused by cancer because physical functioning among survivors did not differ much from an age-matched normative population. Both younger and older long-term cancer survivors visited their medical specialist often but used additional care services after cancer treatment only sporadically.

Young non-Hodgkin lymphoma survivors, but not prostate and endometrial cancer survivors, reported a somewhat lower HRQL compared to the normative population while older cancer survivors did not report lower scores compared to the norm. Our results contradict the results of a study on cancer and non-cancer patients in Medicare managed care that showed that both younger (65–74 years) and older (⩾75 years) cancer survivors had significantly ($p < 0.0001$) lower scores on all SF-36 subscales compared to younger (65–74 years) and older (⩾75 years) non-cancer patients.[19] Although these effects were statistically significant, it is unknown if they were clinically meaningful because subscales were not linearly converted to a 0–100 scale according to standard scoring procedures.[20] For this reason, our scores can not be compared to the scores in that study. In addition, our results contradict

Table 3 – Mean SF-36 scores and standard deviation (SD) for long-term survivors according to age (<70, ⩾70) at time of questionnaire

SF-36 scales	Mean (SD)					
	Non-Hodgkin's lymphoma		Endometrial cancer		Prostate cancer	
	<70 years, N = 155	⩾70 years, N = 70	<70 years, N = 177	⩾70 years, N = 106	<70 years, N = 135	⩾70 years, N = 469
Physical functioning	77.4 (23.8)**	60.5 (28.1)	77.2 (21.3)***	51.2 (29.6)	77.7 (23.0)***	65.1 (28.3)
Role-physical	67.3 (41.3)**	61.4 (43.8)	71.5 (39.7)*	51.1 (42.3)	74.0 (37.7)**	63.7 (42.9)
Role-emotional	84.7 (31.8)	72.9 (40.2)	76.5 (38.1)**	64.0 (45.8)	77.8 (37.9)	75.5 (39.4)
Vitality	61.4 (21.4)	61.1 (19.0)	65.4 (19.0)	61.1 (18.1)	68.4 (21.7)	66.5 (20.7)
Mental health	77.3 (16.3)*	76.4 (18.4)	72.9 (17.3)	75.5 (18.1)	75.7 (17.4)*	77.6 (18.5)
Social functioning	81.7 (20.9)	77.5 (25.2)	81.9 (19.9)	78.3 (23.0)	84.4 (21.0)	80.9 (23.7)
Bodily pain	81.6 (22.3)	77.6 (24.8)	76.9 (22.8)	70.9 (26.0)	82.7 (21.6)	79.7 (23.5)
General health perception	57.6 (24.8)	57.5 (19.9)	63.6 (20.3)	59.1 (19.7)	62.4 (20.6)	59.3 (19.7)
Physical component scale	45.7 (11.5)***	42.2 (10.3)	47.6 (9.8)***	39.7 (11.5)	47.8 (10.0)***	44.0 (10.7)
Mental component scale	52.2 (8.9)***	51.9 (10.2)	50.4 (9.8)	52.4 (10.3)	51.6 (10.4)***	53.6 (9.2)

* $p < 0.05$.
** $p < 0.01$.
*** $p < 0.001$; difference between those <70 years of age and those 70 years and older. p-Value was adjusted for stage, age at diagnosis, treatment, time since diagnosis, education, marital status and comorbidity.

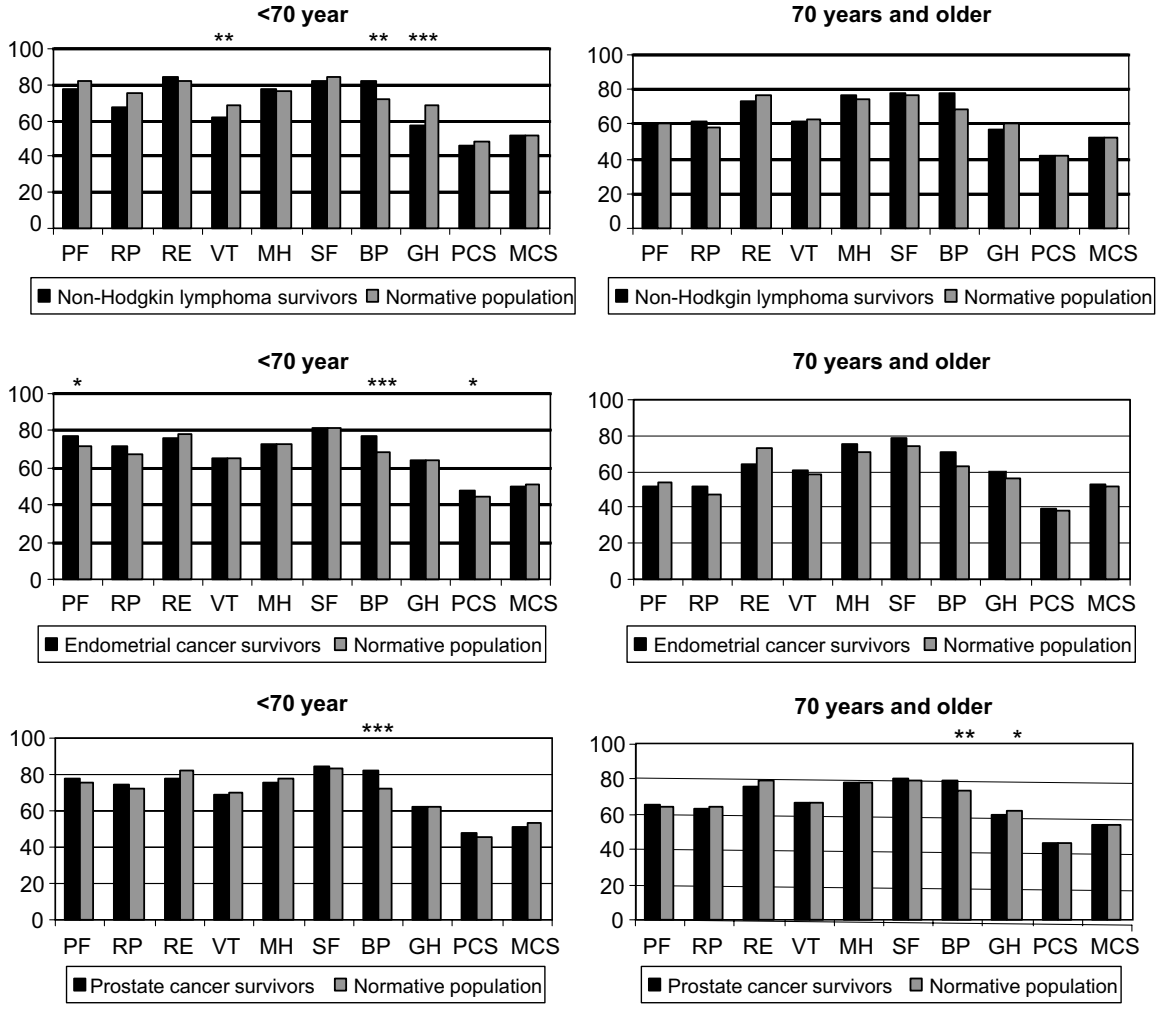

Fig. 2 – Unadjusted SF-36 subscale scores: survivors versus an age- and gender-matched normative population according to age groups.

Table 4 – Multivariate linear regression model evaluating independent variables for SF-36 subscale scores

Independent variable	SF-36 subscales[a]									
	PF	RP	BP	GH	VT	SF	RE	MH	PCS	MCS
<70 year										
Age (time of questionnaire)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Time since diagnosis	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Non-Hodgkin's lymphoma	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Prostate cancer	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Endometrial cancer	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Tumour stage	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Radiotherapy	NS	NS	NS	NS	NS	NS	NS	−0.12*	NS	NS
Surgery	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Chemotherapy	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Hormonal Therapy	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Wait and see	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Comorbidity	−0.22***	−0.24***	−0.29***	−0.25***	−0.17***	−0.19***	−0.11*	NS	−0.31***	NS
Marital status	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Education	0.17***	NS	NS	NS	NS	NS	0.11*	NS	NS	NS
Occupation	0.10*	0.14**	NS	0.16**	NS	NS	0.15*	0.12*	NS	0.12*
⩾70 year										
Age (time of questionnaire)	−0.22***	−0.14**	NS	−0.09*	−0.10*	−0.11**	−0.12**	NS	−0.15**	NS
Time since diagnosis	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Non-Hodgkin's lymphoma	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Prostate cancer	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Endometrial cancer	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Tumour stage	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Radiotherapy	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Surgery	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Chemotherapy	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Hormonal Therapy	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Wait and see	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Comorbidity	−0.17***	−0.17***	−0.24***	−0.23***	−0.20***	−0.15***	−0.09*	−0.12**	−0.20***	−0.14**
Marital status	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Education	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Occupation	NS	0.10*	NS	0.11**	0.11**	NS	NS	NS	0.12**	NS

SF-36, short form-36; PF, physical functioning; RP, role limitations physical health; BP, bodily pain; GH, general health; VT, vitality, SF, social functioning; RE, role limitations emotional problems; MH, mental health; PCS, physical component scale; MCS, mental component scale.
a Standardised beta coefficients.
* $p < 0.05$.
** $p < 0.01$.
*** $p < 0.001$.

Table 5 – The percentage of contact within the last 12 months with a general practitioner and medical specialist between cancer survivors and an age-matched normative population

	Non-Hodgkin lymphoma		Endometrial cancer		Prostate cancer	
	<70 years, N = 155	⩾70 years, N = 70	<70 years, N = 177	⩾70 years, N = 106	<70 years, N = 135	⩾70 years, N = 469
% Visited general practitioner						
Survivors	82	95	91	92	89	88
Controls	78	88	85	89	82	86
% Visited specialist						
Survivors	87***	92**	71**	71**	91***	94***
Controls	48	61	54	58	61	63

Data collected by Statistics Netherlands in 2003.
*$p < 0.05$; **$p < 0.01$; $p < 0.001$; difference between survivors and controls.

the results of a Swedish study on quality of life in older persons with and without cancer.[21] Results of that study showed that cancer patients (>75 years) reported lower scores on the SF-12 physical and mental component scales compared to a normative population without cancer. However, these differences were only statistically significant and not clinically meaningful. Furthermore, this study included patients *with cancer* and not cancer survivors and therefore is not easily

comparable to our study. A study on breast cancer survivors indirectly confirmed the findings from our multivariate linear regression model. Advanced age had the same main effect in breast cancer survivors ($n = 173$) as well as in a matched control group ($n = 176$). Namely, a greater number of diagnosed medical conditions caused limitations in activities.[22]

Long-term prostate and endometrial cancer survivors reported lower pain levels compared to the normative population. We suspect that this is either a chance finding or, if real, may reflect a 'response shift' phenomenon whereby individuals redefine their internal standards for rating their level of functioning or symptoms (in this case pain) as a result of their illness experience.[5,23,24] Patients may accept pain as an inevitable consequence of having been treated for cancer, a condition they perceive as life threatening. Common benign aches and pains, such as headache, may then be considered as less burdensome by cancer survivors than by their general population counterparts.

Furthermore, this study showed that HRQL in endometrial and prostate cancer survivors was comparable, and not lower, compared to a normative population. This can be explained by the fact that most people not only experience negative but also certain positive effects after an encounter with a stressor.[25–31] This is also known as 'benefit finding' which can be described as the identification of benefit from adversity.[32] Furthermore, patients may experience posttraumatic growth[31,33–37] which is described as 'the experience of significant positive change arising from the struggle with a major life crisis'.[38] Benefit finding and posttraumatic growth may explain, at least in part, the absence of differences in HRQL between prostate and endometrial cancer survivors compared to the age-matched norm population.

Older long-term cancer survivors experienced a lower physical functioning compared to younger survivors. This difference between older and younger survivors was confirmed by a study among cancer survivors that compared survivors aged 65–74 ($n = 22.106$) to those aged 75 and older ($n = 21.651$). Individuals aged 65-74 had significantly higher mean scores on all SF-36 scales compared to those aged 75 and older.[19] This difference was also indirectly confirmed by a study that compared differences in HRQL by therapy for both young (<75) and old ($\geqslant 75$) long-term prostate cancer survivors. Although this study only showed mean SF-36 scores for both young and old survivors by therapy and did not test for significance between the two, the big differences in mean scores between old and young survivors on some subscales are definitely an indication[4].

Both younger and older cancer survivors visited their medical specialist, but not their general practitioner, more often compared to the general population. These same results were also found in another article based on this database.[39] However, in that particular study, we did not make a difference for age groups. A difference in survivors under and above the age of 75 was made in a Dutch study among 10-year breast cancer survivors and the results confirm our findings.[40] The proportion of both younger and older breast cancer survivors, who visited a medical specialist in the past 12 months, was significantly higher compared to controls while there were no differences in visits to a general practitioner. Finally, our results partly confirm the results of a Norwegian study among long-term cancer survivors.[41] The use of specialist health care services was significantly higher among cancer survivors (49%) than among controls (27%) and this difference remained, even 10 years after diagnosis, while the frequency of visiting a general practitioner normalised over time.

The high proportion of survivors who visited a medical specialist in the past 12 months compared to the normative population can partly be explained by routine annual follow-up examinations. For example, patients with non-Hodgkin's lymphoma are in follow-up for at least 5 years (Dutch guidelines; http://www.oncoline.nl). However, most of them stay longer in follow-up. Additionally, prostate cancer patients visit their urologists only 10 years after diagnosis for annual follow-up. These follow-up examinations explain, at least in part, the higher proportion of survivors visiting a medical specialist as compared to the general population.

In our questionnaire, we asked patients whether they received any additional care for cancer-related problems after cancer treatment. Survivors only sporadically received additional support. However, the survivors in our study were diagnosed and treated between 1989 and 1998. Additional care after cancer treatment was not common in those days. It would be interesting to ask the same question to patients diagnosed and treated nowadays in order to estimate the increase in the percentage of survivors receiving additional care after cancer.

Several limitations of the current study should be noted. First, only 13% of patients could not be sent a questionnaire because of unverifiable addresses and 20% of patients who were sent a questionnaire did not respond, so we do not know what their current health status is. Non-respondents were significantly older; more often diagnosed with stage I disease and less often treated with chemotherapy than respondents or patients with unverifiable addresses. It is therefore possible that our results cannot be generalised to very old patients, patients diagnosed with stage I disease and patients treated with chemotherapy. Second, patients with disease progression were excluded from our analysis. Information on HRQL of these patients is therefore lost. However, we experienced difficulties in reporting HRQL of this heterogeneous subset of patients because additional tumour characteristics for disease progression (e.g., localisation, stage, grade and time since diagnosis) were unknown. Our results can only be generalised to survivors with the best prognosis namely, those who do not show any signs of disease progression. Third, it is more difficult to draw conclusions from a cross-sectional study than a longitudinal study. No conclusions can be drawn on the nature and direction of the relationships. Since we only included disease-free survivors in our analyses, we cannot generalise the results of our study to those who have disease progression. Fourth, we excluded patients aged 75 and older *at diagnosis* because it was expected that they would have difficulty in completing a self-report questionnaire without assistance. However, important information on the HRQL and health care utilisation among the very elderly is now missing. Offering the elderly assistance with completing the questionnaire, like giving information by telephone, completing the interview by telephone, or offering house-visits by a research assistant who would help them to fill out the questionnaire could

probably increase the participation of elderly patients. Finally, we measured HRQL with the SF-36. However, it is also important that assessment of HRQL incorporates issues of importance to individual older people by broadening the scope of the measurement instruments, thus representing more validly the HRQL status of older patient groups.[42]

Despite these limitations, the results of this study form an important contribution to the limited information available on HRQL and health care utilisation in the growing group of elderly long-term cancer survivors. This study included an unselected group of cancer patients, treated in various general hospitals, and not in centres of excellence or tertiary referral centres in contrast to most randomised trials. Results of a population-based study can more easily be generalised to the general population compared to results of randomised controlled trials. In addition, the large number of participants in this study and the high response rate of this study allow us to extrapolate to the broad population of long-term cancer survivors without disease progression.

Our study provided insight into the HRQL and health care utilisation of elderly long-term cancer survivors. HRQL of older and younger survivors is comparable, with the exceptions of physical functioning which is lower in older survivors. This difference in physical functioning was probably not caused by cancer because physical functioning among cancer survivors did not differ much compared to an age-matched normative population. This can be explained in numerous ways. For example, lower HRQL among elderly survivors compared to younger survivors can be due to a natural ageing process. In addition, a lower HRQL between young survivors and the (young) normative population can be caused by the fact that these patients were relatively 'healthy' at diagnosis and thus were treated more aggressively compared to older cancer survivors who were more fragile. Older cancer patients were probably treated less aggressively and therefore do not differ much from the (old) normative population. Furthermore, it is possible that older cancer survivors experience the same HRQL compared to the normative population because only the most though survivors survive while the more weaker patients have already died; 'survival of the fittest'.

Conflict of interest statement

None declared.

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